

Coping styles of parents of children and adolescents with acquired brain injury in the chronic phase

Citation for published version (APA):

Prihadi, E. J., Dings, F., & van Heugten, C. M. (2015). Coping styles of parents of children and adolescents with acquired brain injury in the chronic phase. *Journal of Rehabilitation Medicine*, 47(3), 210-215. <https://doi.org/10.2340/16501977-1913>

Document status and date:

Published: 24/11/2015

DOI:

[10.2340/16501977-1913](https://doi.org/10.2340/16501977-1913)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

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ORIGINAL REPORT

COPING STYLES OF PARENTS OF CHILDREN AND ADOLESCENTS WITH ACQUIRED BRAIN INJURY IN THE CHRONIC PHASE

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Objective: To investigate the types of coping strategies used by parents of children with acquired brain injury in the chronic phase and the relationship between their coping styles and psychosocial functioning.

Design: Cross-sectional study (April–May 2013).

Subjects: Parents ($n=42$) of 28 children with acquired brain injury (>6 months post-injury).

Methods: Parents completed the Utrecht Coping List, Life Satisfaction Questionnaire 9, Caregiver Strain Index, and Family Assessment Device.

Results: The use of coping strategies among fathers did not differ from that among men from the standardization population ($t_{14}=0.96$, $p=0.35$ and $t_{14}=0.61$, $p=0.55$, respectively). However, mothers used more emotion-focused coping strategies than women in the standardization population ($t_{26}=3.27$, $p=0.00$), while there was no difference on the problem-focused coping strategies ($t_{26}=-1.75$, $p=0.09$). Parents who used emotion-focused coping styles exhibited lower family functioning, higher strain and lower quality of life, while those who used problem-focused coping styles exhibited higher strain.

Conclusion: Parents of children with acquired brain injury need proper treatment to improve their psychosocial functioning. In particular, treatments should be developed that aim at changing the parents' maladaptive coping styles into less maladaptive ones. Thus, more attention should be focused on the psychological well-being of parents of children with acquired brain injury in the chronic phase.

Key words: brain injuries; child; parents; coping behaviour; psychosocial factors; rehabilitation.

J Rehabil Med 2015; 47: 210–215

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Accepted Aug 29, 2014; Epub ahead of print Nov 24, 2015

INTRODUCTION

Acquired brain injury (ABI) in children refers to any brain injury that occurs at any time from early foetal development onwards (1). ABI leads to several important changes that affect the daily functioning of children with ABI, depending on the age, type

and severity of the injury (1). These children may show disruptions in cognitive functioning (e.g. weak executive functions, language and communication problems, poor attention, etc.), emotional and behavioural functioning (e.g. anxiety, depression, impulsiveness, anger, etc.) and physical functioning (e.g. visual and hearing impairments, sensory loss, etc.) (e.g. 2). Furthermore, ABI can lead to changes in functioning of the family system (3). One study showed that the more severe the traumatic brain injury (TBI) of the child, the higher the overall injury-related burden the family members experience across several domains (i.e. worrying about the injured child, the relationships with other family members or partners) (4). Thus, not only does ABI have profound consequences for the child, it also affects the whole family (1).

Family members play an important role in supporting the child after the injury and during the rehabilitation process (3). The negative consequences on the child after the brain injury can place high demands and additional responsibilities on the family, especially on the primary caregivers. In addition to the caregivers' constant supervision of the child, the caregiver can experience guilt, blame and anger associated with the injury, and a lack of knowledge about how to obtain appropriate therapy and education for their child (1). Caregivers therefore have to learn how to use their coping strategies efficiently to deal with these significant consequences and to manage the stress of the early diagnosis and treatment of their child (5).

According to Lazarus (6), coping can be defined as consisting of the behavioural and cognitive efforts a person utilizes to handle psychological stress. One important psychological theory of coping is that of Lazarus & Folkman (7), which tries to clarify the differences between people with regard to how they respond to the same stressor with different levels of stress. Problem-focused coping and emotion-focused coping are the 2 major functions related to coping, according to Folkman et al. (8). Problem-focused coping is about taking action on the self or the environment to handle the stress, while emotion-focused coping deals with the problem by monitoring the stressful emotions through altering the perceived meaning of the problem. For this study, we applied the theory of Lazarus & Folkman because of its influence in coping research for ABI (9–11).

Several studies of patients with ABI indicate that problem-focused coping is associated with experiencing adaptation and less psychological distress in controllable situations, while emotion-focused coping strategies are associated with avoid-

ance coping and negative adaptation in controllable situations (12–15). Moreover, there seems to be a difference in the type of coping strategies used, depending on the time period after the onset of ABI. Specifically, several studies found an increase in the use of emotion-focused coping in the (sub)acute phase following injury (i.e. between 0 and 6 months post-injury) and a decrease in the chronic phase (i.e. after 6 months post-injury), while in the acute phase less of a trend of problem-focused coping occurs (16, 17).

Not much is known about the coping strategies of family members of patients with ABI. Concerning the coping strategies of parents of adult patients with ABI, one study indicates that parents of patients with TBI who use more emotion-focused coping strategies experience more distress than those who utilize more problem-focused coping strategies (18). However, Sander et al. (17) reported that caregivers use more emotion-focused coping styles in the acute phase, while the use of this coping style decreases in the chronic phase.

Even less is known about the coping strategies of caregivers of paediatric ABI patients. According to Fuemmeler et al. (19), parents of a child with a brain tumour who use greater levels of emotion-focused coping styles experience an increased level of post-traumatic stress and general distress. However, more research is needed concerning the coping strategies used by caregivers of children with ABI.

The aims of this study, therefore, were to identify the types of coping strategies that parents of children with ABI use in the chronic phase after injury and the relationship between their coping styles and psychosocial functioning (i.e. family functioning, life satisfaction, caregiver strain). Such information can help in developing appropriate support strategies and therapy programmes in child rehabilitation programmes.

Based on previous research, we formulated 2 research questions. The first question is whether the coping strategies of the parents of children with ABI in the chronic phase differ from those of the normal population. It has been shown that the use of emotion-focused and problem-focused strategies by caregivers of adult patients with ABI in the chronic phase does not differ from that of the standardization sample (20). Therefore, we expected no difference between the use of coping strategies of the parents of children with ABI in the chronic phase and that of the normal population. The second question concerns which coping strategy is associated with improved psychosocial functioning. Previous studies have shown that emotion-focused coping strategies are related to a higher level of stress, while problem-focused coping strategies are more important in the adaptation process for parents of adult patients with ABI in the chronic phase (16, 18). Thus, we hypothesized that those parents who employ a problem-focused strategy have improved psychosocial functioning in terms of having a higher level of family functioning, a higher quality of life and lower level of strain.

METHODS

This study had a cross-sectional design.

Participants

Approximately 130 parents of children with an ABI in the chronic phase (defined here as >6 months post-injury) who are currently being treated or had been referred to the child rehabilitation centre in Adelante (The Netherlands) were invited to participate in this study. Children with moderate to severe ABI are referred for rehabilitation to this centre. In case of severe behavioural problems, children are referred to mental health care instead. Children and adolescents with a maximum age of 20 years are admitted to the child rehabilitation centre.

Inclusion criteria for this study were: (i) the parent was living in the same household as the patient; (ii) and has adequate knowledge of the Dutch language to be able to understand and complete the questionnaires; (iii) the child is currently aged between 1 and 25 years. Parents whose child was in a vegetative state were excluded from this study. The study was approved by the ethics committee of the Faculty of Psychology and Neuroscience. All participating parents provided written informed consent.

Measures

Utrecht Coping List (UCL). Coping was assessed with the UCL (21), a 47-item self-report questionnaire used to measure 7 styles of coping, which have been factor-analytically derived. Furthermore, it has a well-documented validity and reliability (20). Participants were asked to indicate on 4-point scales how frequently they apply certain coping strategies (1 = seldom/never, 2 = occasionally, 3 = frequently, 4 = very often). A higher score indicates more use of that specific coping style. In this study 2 of the 7 scales were used: the active problem-solving coping scale and the passive emotion-focused coping scale. The active problem-solving coping scale corresponds to active coping and contains 7 items (e.g. tackle a problem at once, regard problems as a challenge, remain calm in difficult situations), while the passive emotion-focused coping scale corresponds to passive coping and contains 7 items (e.g. isolate oneself from others, worry about the past, take refuge in fantasies) (22). The scores on both scales range from 7 to 28; a higher score indicating more use of that coping style. The UCL has good psychometric properties (20) Normative data was collected from the UCL manual (21).

Family Assessment Device (FAD). The FAD is a 60-item self-report questionnaire that measures aspects of communication within the family (23). The FAD contains 7 subscales of family functioning, of which the General Functioning (GF) scale was used for the present study. This subscale consists of 12 items that evaluate the general problems of family relationships. FAD uses Likert items, each with 4 answer choices (1 = totally not agree, 2 = not agree, 3 = agree, 4 = totally agree). The scores are averaged and range from 1 to 4, with a score above 2 indicating an unhealthy family situation. According to de Wachter et al. (24), the Dutch version of the FAD shows appropriate psychometric properties in which the General Functioning scale has a Cronbach's alpha of 0.82–0.92.

Life Satisfaction Questionnaire 9 (LiSat-9). The LiSat-9 is a self-report questionnaire that measures the quality of life satisfaction (25). It focuses on important life domains and contains 1 question about general life satisfaction and 8 questions on domain-specific life satisfaction: vocational situation, financial situation, sexual life, partnership relations, family life, contact with friends, self-care management and leisure situations. Participants answered the 9 questions on a 6-point scale (1 = very dissatisfied, 2 = dissatisfied, 3 = rather dissatisfied, 4 = rather satisfied, 5 = satisfied, 6 = very satisfied). The mean scores range from 1 to 6; a score lower than 4.5 is indicative of dissatisfaction. The Dutch LiSat-9 shows satisfactory internal consistency (Cronbach's alpha 0.74–0.85) (25, 26).

Caregiver Strain Index (CSI). The CSI is a self-report questionnaire that measures the experience of strain by caregivers. It consists of 13 statements with dichotomous yes or no answers (score range 0–13). Caregivers who receive a total score of 7 or more are thought to experience a high burden. Internal consistency (Cronbach's alpha) is 0.86 (27).

Procedure

For this study, the database of patients with brain injury who are currently being treated or had been referred to the child rehabilitation centre between 2000 and 2013 were considered for participation. The parents were approached by an invitation letter of their treating rehabilitation physician sent in April 2013 to participate in this study. Demographic information about the patients and parents and lesion characteristics of the patients (gender; level of educational attainment; date of birth; type of lesion; location of lesion) were collected from the medical files of the patients after obtaining written permission from the parents. The parents who considered themselves eligible on the basis of the criteria for inclusion and who wanted to participate in the study were asked to respond within 2 weeks by signing the informed consent and returning the questionnaires (UCL, LiSat-9, FAD, CSI) in the enclosed stamped envelope. If after 2 weeks no response had been received, a reminder was sent. Assistance with completing the questionnaires was offered by the researcher. Data were collected in April and May 2013.

Statistical analyses

Level of education (LE) was assessed according to the structure of the Dutch education system (28). Furthermore, the parents were grouped into 3 levels: those with primary education (LE low); those with secondary education (LE average); and those with tertiary education (LE high). The educational level was dummy coded with 2 dummies (LE low and LE high), where LE average was labelled as the reference category. Scores on the questionnaires were entered as continuous variables.

First, descriptive analyses were performed on demographic and medical variables, coping and psychosocial functioning. To answer the first research question, 4 1-sample *t*-tests were carried out to test differences between the men in the study and the men in the standardization sample, and between the women in the study and the women in the standardization sample on the active problem-solving coping scale and the passive emotion-focused coping scale.

To answer the second research question, 3 linear regression analyses for the possible associations between the coping strategies of the parents and their psychosocial functioning were performed, with dependent variables CSI, LiSat-9 and FAD-GF. The independent variables in each model were the scores on the active problem-solving coping scale and the passive emotion-focused coping scale. The level of educational attainment of the parent was included as covariate. Assumptions for regression analyses were checked. We believe we have sufficient power to perform these analyses, taking into account a rule of thumb of a minimum of 10 persons for each independent variable.

In all models, the independent variables were entered together through forced entry. Alpha was set at 0.05. Analyses were performed with SPSS 19.0 for Windows 7.

RESULTS

Injury and demographic characteristics

Questionnaires were sent to 130 parents. The final sample comprised 42 parents (response rate 32%) of 28 children. There were no missing data in the final sample. The reasons for declining to participate in this study were mainly work-related factors or finding the questionnaires too personal or confrontational. For 14 children, both parents participated in this study, while 14 parents participated without their partners due to work-related factors. Furthermore, most participants were women (64%) and had an average (45%) or high (45%) level of education. The mean age of the parents was 45 years (SD 5.3), while the mean age of the patients was 13.6 years (SD 4.8; median 14) (Table I).

Table I. Injury characteristics of the patient ($n=28$), and demographic characteristics of the patients and parents ($n=42$)

Characteristics	
Age, years, mean (SD) [range]	
Patient	13.6 (4.8) [4.0–23.0]
Caregiver	45.0 (5.3) [33.0–54.0]
Gender, male, n (%)	
Patient	20 (47.6)
Caregiver	15 (35.7)
Gender, female, n (%)	
Patient	8 (19.0)
Caregiver	27 (64.3)
LE, n (%)	
Caregiver	
Low	4 (9.5)
Average	19 (45.2)
High	19 (45.2)
Type of injury, n (%)	
CVA	2 (4.8)
TBI	20 (47.6)
Other	6 (14.3)
Side of injury, n (%)	
Left	3 (7.1)
Right	2 (4.8)
Bilateral	4 (9.5)
Unspecified	19 (45.2)

LE: level of educational attainment; CVA: cerebrovascular accident; TBI: traumatic brain injury; Other: tumour ($n=4$), meningitis ($n=2$); SD: standard deviation.

Coping and psychosocial outcomes of the caregivers

Table II shows that, for the men, UCL scores of the parents on the active problem-solving scale and the passive emotion-focused scale were average compared with the standardization group ($t_{14}=0.96$, $p=0.35$ and $t_{14}=0.61$, $p=0.55$, respectively). For women, the UCL scores of the parents on the active problem-solving scale were average compared with the standardization group ($t_{26}=-1.75$, $p=0.09$), while the UCL scores on the passive emotion-focused scale were significantly different from those of

Table II. Coping and psychosocial outcomes of caregivers ($n=42$)

Outcomes	Mean (SD)	Median	Range
UCL (active scale)			
Men	19.2 (3.6)	20.0	12.0–25.0
Women	18.2 (3.4)	19.0	8.0–22.0
Standardization group men ^a	18.3 (3.5)		
Standardization group women ^a	19.3 (5.1)		
UCL (passive scale)			
Men	11.3 (3.6)	11.0	7.0–20.0
Women	13.2 (3.7)	13.0	8.0–22.0
Standardization group men ^a	10.7 (2.9)		
Standardization group women ^a	10.9 (5.4)		
CSI	6.6 (3.6)	6.5	1.0–13.0
LiSat-9	4.4 (0.9)	4.7	1.8–6.0
FAD-GF	1.9 (0.5)	1.8	1.0–3.1

^aThe standardization group of men consists of men between the ages of 19 and 65 years ($n=1,493$). The standardization group of women consists of women between the ages of 18 and 65 years ($n=1,721$; (21).

UCL: Utrecht Coping List; CSI: Caregiver Strain Index; LiSat-9: Life Satisfaction Questionnaire; FAD-GF: Family Assessment Device-General Functioning; SD: standard deviation.

Table III. Multiple linear regression models for caregiver's psychosocial outcome measures (n = 42)

Variable	B	β	CI	p-value	R ²
Model 1: FAD-GF score					
(constant)	0.67		-0.23-1.57	0.137	
Active	0.01	0.06	-0.03-0.04	0.667	
Passive	0.09	0.72	0.06-0.12	<0.001*	
LE low	-0.02	-0.02	-0.39-0.34	0.898	
LE high	-0.2	-0.21	-0.42-0.03	0.087	56.5
Model 2: CSI score					
(constant)	-13.33		-20.33-(-6.32)	<0.001*	
Active	0.54	0.53	0.26-0.82	<0.001*	
Passive	0.80	0.83	0.55-1.04	<0.001*	
LE low	0.24	0.02	-2.62-3.10	0.868	
LE high	-0.21	-0.03	-1.98-1.56	0.813	54.8
Model 3: LiSat-9 score					
(constant)	7.01		5.12-8.91	<0.001*	
Active	-0.03	-0.11	-0.10-0.05	0.454	
Passive	-0.18	-0.75	-0.25-(-1.22)	<0.001*	
LE low	0.60	0.20	-0.15-1.36	0.113	
LE high	0.20	0.11	-0.27-0.67	0.400	51.3

* $p < 0.05$.

B: unstandardized regression coefficient; β : standardized regression coefficient; CI: 95% confidence interval; Active: active problem-solving scale of UCL; Passive: passive emotion-focused scale of UCL. Coding of the independent variables: LE low: low educational attainment=1, average or high educational attainment=0; LE high: high educational attainment=1, low or average educational attainment=0.

UCL: Utrecht Coping List; CSI: Caregiver Strain Index; Lisat-9: Life Satisfaction Questionnaire; FAD-GF: Family Assessment Device – General Functioning.

the standardization group ($t_{26} = 3.27, p = 0.00$). Specifically, the mean score of the UCL scores on the passive emotion-focused scale of female caregivers (mean = 13.2) was significantly higher than the mean score of the standardization group (mean = 10.9). Thus, the women in this study used more passive coping strategies than the women in the standardization group.

Table II also shows that the mean score of CSI was below the cut-off point of 7 (mean = 6.6). Twenty-one parents (50%) experienced a high level of strain. Furthermore, the LiSat-9 showed that parents were, on average, not satisfied with life, indicated by a mean score of 4.4. Specifically, 18 parents (43%) reported a low quality of life, indicated by a score of less than 4.5. Lastly, the mean FAD-GF score of the parents is 1.9, which is just below the cut-off value of 2. Sixteen parents (38%) experienced unhealthy family functioning, indicated by a score of 2 or above.

Associations between caregivers' coping styles and caregivers' quality of life, strain and family functioning

Table III shows that a higher use of passive coping styles was associated with higher FAD-GF scores, higher CSI scores and lower LiSat-9 scores. Thus, these results show more family dysfunction, higher levels of strain and a lower quality of life. The active problem-solving scale did not reach significance with the dependent variables FAD-GF and LiSat-9. However, it was shown that a higher use of active coping styles was associated with higher CSI scores. The linear regression models explained 57% of the variance in family functioning, 55% of the variance in strain and 51% of the variance in quality of life. The assumption of homoscedasticity was violated in the LiSat-9 model. After applying a square transformation, the results remained similar. Therefore, we reported the untransformed models.

DISCUSSION

The aims of this study were to identify the types of coping strategies that parents of children with ABI use in the chronic phase, and the relationship between their coping styles and their psychosocial functioning (i.e. family functioning, life satisfaction, caregiver strain). The use of coping strategies of fathers did not differ from those of men from the standardization population. Mothers used more passive coping strategies than women in the standardization population, while there was no difference in the active coping strategies. In addition, parents who used passive coping styles showed lower family functioning, higher strain, and lower quality of life. Parents who used active coping styles showed higher strain.

Contrary to our hypothesis and previous results (20), female caregivers used more passive coping strategies than women in the standardization group, while there was no difference on active coping strategies. A previous study showed that there was no difference between the use of coping strategies of mothers of adult patients with ABI in the chronic phase and women in the normal population (20). A possible explanation is that mothers whose child experienced an ABI early in life have more difficulty with accepting and adjusting to the situation in the chronic phase post-injury. Studies have suggested that parents may be confronted with the reality that the developmental process of their child is interrupted and that it may permanently affect the child's behaviour (29, 30).

Consistent with the results of previous research (20), the use of passive coping styles by the caregivers showed negative relationships with their psychosocial functioning in the chronic phase post-injury. In particular, those who used a passive coping style reported lower family functioning, higher strain, and a lower quality of life.

Inconsistent with our hypothesis, parents who preferred active coping styles showed no effect on family functioning and quality of life. One could expect that taking action results in improved psychosocial functioning. Furthermore, studies have shown that the use of active problem-focused coping styles is associated with the experience of less psychological distress (12–15). Surprisingly, the current study showed that parents with an active coping style experienced a higher strain, which is not in line with the results of the previous study on caregivers of adult patients with ABI (20). The previous results reported that caregivers who preferred an active coping strategy showed no effect on family functioning, quality of life, and strain (20). The reason for the current result is unclear. One possible explanation could be that some active coping styles assessed in this study may contain behaviours that result in ineffective coping with the injury of their child. Active coping behaviours, such as “direct intervention when there are difficulties”, “seeing problems as a challenge” or “to view a problem at several sides” could place a higher strain in the daily lives of the caregivers. This is an important subject for future research.

Limitations and strengths

Some limitations of this study must be addressed. First, the response rate of this study was particularly low (32%), which could indicate the potential for a selection bias in the results and a tendency for a less representative sample than would be obtained with a larger sample (31). Secondly, a cross-sectional design was used; therefore it was not possible to determine cause-and-effect relationships between the coping characteristics and the psychosocial outcome measures. Future research is needed focusing on the causal relationships, which could be studied with the use of an experimental, longitudinal design. Thirdly, the exact time between brain injury and the examination was not included in this study. However, all children were in the chronic phase post-injury (>6 months) and therefore no influence of time since injury would be expected. Fourthly, characteristics of the participating parents before the injury were not well examined. It could be that parents who already had a higher level of pre-existing stress can less effectively cope with the injury of their child (32). Finally, the study sample was heterogeneous in terms of age and type of injury, although this enhances the external validity of the study, being more representative of the population seen in daily clinical practice.

This study also has some strengths. To our knowledge, this is one of the first studies to investigate the effect of parents' coping styles of children with ABI on the psychosocial functioning of the parents. Furthermore, we measured several aspects of psychosocial functioning of parents, which provided a clear summary of the kind of difficulties parents of children with a brain injury face in daily life. Also, we included parents of children with ABI who were currently being treated or who had been referred to a child rehabilitation centre. Thus, the findings of the present study could be generalized to the population of parents currently living in the same household as their children with ABI.

Clinical and research implications

The findings of this study have important clinical and research implications. The results showed that the mothers of children with ABI in the chronic phase used more passive coping strategies than did women from the standardization group. Several studies reported that, in general, women prefer to use emotion-focused coping styles, which is related to an increase in psychological distress (33–35). Thus, it is important that professionals determine the coping skills of mothers of children with ABI at an early phase in order to avoid a further increase in negative psychological consequences.

Another important finding is that the use of a passive coping strategy by parents has a negative effect on their psychosocial functioning in the chronic phase. Therefore, we recommend the development of treatments that focus specifically on changing the maladaptive coping skills of caregivers into ones that are more adaptive for a positive improvement in their psychosocial functioning. Specifically, such treatments should consist of psycho-education about ABI and what kind of coping strategies could be seen as adaptive and maladaptive. In addition, an adaptive coping training for caregivers could be a way to optimize their psychosocial functioning. One study showed that psycho-educational interventions that aim at improving psychological symptoms and coping strategies of caregivers of cognitively impaired and/or physically older adults can have a significant improvement on caregivers' distress (36). In clinical practice we found that parent peer support is highly appreciated; this can be enabled in group meetings consisting of education and sharing of experiences.

Furthermore, it is necessary to examine the coping strategies of the caregivers from the start of the rehabilitation process, in order to detect and monitor those who use a maladaptive coping strategy. This is rarely done in daily practice. There are only a few evidence-based treatment programmes studied that help clients change their maladaptive coping styles into ones that are less passive and maladaptive. However, there are other effective treatments that could help these clients adapt their negative experiences, e.g. cognitive behavioural therapy (CBT) and mindfulness (37, 38).

Future research

Future research should investigate whether increased use of adaptive coping styles leads to an increase in positive psychosocial functioning (i.e. higher family functioning, lower strain and higher quality of life).

Furthermore, it is possible that other factors may have influenced the coping styles of caregivers and their psychosocial functioning, such as the coping strategies used before the injury, social economic status, personality and the amount of social support available. These factors were not investigated in this study. In addition, it would be interesting to explore the relationship between the coping styles of the primary caregivers and the self-reported quality of life of their child. In a previous study of this relationship among adult patients with ABI, it was shown that the coping strategies of the caregivers

were not associated with the self-reported quality of life of the adult patients (20). Moreover, the current study focused only on the primary caregivers of the child. In the study of Wolters Gregório et al. (20), the other family members of the adult patient with ABI completed the FAD-GF, where it was shown that there was no association between the family functioning of the other family members and the quality of life of the adult patient.

Conclusion

This study shows that passive coping styles of parents have a negative effect on their psychosocial functioning. Mothers show a significantly higher use of passive coping styles. Furthermore, parents who utilize an active coping style experience higher strain. These results show that, not only children with ABI, but also their parents, need the proper treatment to improve their psychosocial functioning. Thus, more attention should be focused on the psychological well-being of parents of children with ABI in the chronic phase.

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